

## Availability of psychological care in pediatric diabetes centers – a real need?

Dostępność opieki psychologicznej w placówkach diabetologii dziecięcej – realna potrzeba?

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### Abstract

The role of a multidisciplinary diabetes team (MDT) in the treatment of a person with diabetes is emphasized by both Polish and international recommendations. The importance of the availability of psychological care for the well-being and mental health of individuals (and their caregivers), as well as for diabetes management and medical outcomes, is a subject of numerous analyzes. Despite the recommendations and research showing the benefits of psychological intervention and support, there is a scarcity of data on the real availability of such care, both in Poland as well as worldwide.

#### Key words:

diabetes mellitus, psychological care, mental disorders, multidisciplinary team, self-management.

### Streszczenie

Rolę multidyscyplinarnego zespołu diabetologicznego w leczeniu osoby z cukrzycą podkreślają zarówno polskie, jak i międzynarodowe zalecenia. Znaczenie dostępności opieki psychologicznej dla samopoczucia i zdrowia psychicznego osób z cukrzycą (i ich opiekunów), a także dla wyników leczenia cukrzycy jest przedmiotem licznych analiz. Pomimo rekomendacji i badań pokazujących korzyści z interwencji i wsparcia psychologicznego, brakuje danych na temat rzeczywistej dostępności takiej opieki zarówno w Polsce, jak i na świecie.

#### Key words:

cukrzyca typu 1, opieka psychologiczna, zaburzenia psychiczne, multidyscyplinarny zespół, samoopieka.

## Introduction

The incidence of type 1 diabetes (T1D), which is the most common type of diabetes in the pediatric population, is increasing [1]. By requiring daily glycemic control, analysis of food intake and physical activity and self-management, T1D remains a chronic illness with no days off. Regardless of the type of treatment, the diagnosis requires many radical changes in the lives of the child/adolescent and their caregivers. The intensive development of technological solutions in diabetes care, such as continuous or flash glucose monitoring systems (CGM, FGM), smart pens, and personal insulin pumps, including hybrid closed-loop systems, allows to improve glycemic control and positively affects the quality of life, reduce the mental and physical burden associated with diabetes self-management of persons with diabetes (PWD) [2]. Data from the SWEET registry show an improvement in glycemic control and a lower number of diabetes ketoacidosis (DKA) episodes in those using an insulin pump or CGM system or both [3]. A systematic review by

Messer *et al.* indicated that the technologization of T1D treatment leads to an improvement of glycemic outcomes (hemoglobin A1C, time in range – TIR) in youth with T1D, when the needs associated with financial and, more important, educational support, are met [4]. This indicates that the high advancement and availability of new technologies are not the only solution for improving diabetes care and support, and probably might also not be the most important determinant of better treatment outcomes.

As living with diabetes and the responsibility associated with continuous diabetes management encounters significant burden: 24 hours a day, 365 days a year, and it affects the normal day-to-day living of PWD and their carers, for example, school and career choice. The national (Diabetes Poland) and international diabetes associations highlight the crucial role a multidisciplinary diabetes team (MDT), which should include, in addition to clinicians, nursing and educational care and dietary advice, as well as psychological, psychiatric and social care support.

The aim of this manuscript is to present the role of psychological care and to review the data on the implementation of the Polish and international recommendations regarding the availability of such care in pediatric diabetes centers.

### Psychological issues in children with type 1 diabetes

*Diabetes distress* denotes the widely understood negative emotions related to life with T1D and the constant need for self-management and therapeutic decision-making about insulin doses and interventions to maintain acceptable glucose values. A large systematic review has shown that similar to the adult population, the proportion of adolescents experiencing *diabetes distress* is high and is often associated with suboptimal glycemic control [5].

Attention should also be paid to the phenomenon known as “diabetes burnout”, which is described as fatigue associated with the constant need to control the disease and a feeling of frustration related to, inter alia, the inability to achieve therapeutic goals. This frustration is so intense, that it often causes the inability to manage diabetes, when people do not manage or control diabetes at all, thus do not meet any of the therapeutic goals, and avoid medical appointments. It also causes the feeling of constant guilt and blame and demotivation in caring for one’s health [6].

Many scientific studies emphasize the increased risk of eating disorders in adolescents with T1D, depression (among others major depressive disorder) and anxiety, including children and adolescents, and their caregivers, especially at T1D onset [7, 8]. Although the onset of T1D is a great emotional challenge for the whole family, depression, anxiety, diabetes distress etc. can occur at any stage of life with diabetes. Psychological well-being is important not only for the overall well-being of a PWD, but influences the treatment of diabetes and its outcomes. The evidence shows that mental disorders are associated with poorer glycemic control and an increased risk of associated hospitalizations. More severe depressive symptoms are directly related to poorer glycemic control, worsened motivation, and poorer quality of life [9]. Mental health disorders are often observed in children and adolescents with recurring episodes of diabetic ketoacidosis (DKA) compared to those with more optimal glycemic control. This suggests that repeated hospitalizations due to DKA may indicate that the patient needs psychological support and/or psychiatric intervention.

Moreover, PWD are also at risk of other psychological problems, such as disordered eating behaviors, mild cognitive functioning and school performance decrements, parental distress as well as decreased quality of life [9, 10].

Therefore, the recommendations of Diabetes Poland, as well as the international guidelines from the American Diabetes Association (ADA) and the International Society for Pediatric and Adolescent Diabetes (ISPAD) address the need for and highlight the importance of psychological care. According to the abovementioned recommendations, the mental health of a PWD should be assessed from the diagnosis of diabetes,

and later at any stage of life on a regular basis to screen for mental health disorders that may affect PWDs [11–13].

It is proven to be beneficial to use screening standardized questionnaires, such as the Diabetes Eating Problems Survey -Revised (DEPS-R) [14], or a questionnaire assessing the risk of depression, previously used in adults with diabetes – CES-D [15, 16], Problem Areas in Diabetes (PAID) or widely used questionnaires assessing the diabetes distress (Diabetes Distress Scale) [5]. Those dedicated questionnaires are available in English for adolescents with diabetes and their caregivers, respectively: PAID-T and P-PAID-T [17] and T1-DDS and are recommended by the ADA. Diabetes Poland also advises using generally available questionnaires, such as the Well-Being Index developed by the World Health Organization (WHO) [18], Health-Related Quality of Life [19] and the Patient Health Questionnaire PHQ9 [20] as a useful tool to assess the risk of depressive disorders in patients. Both documents are available in Polish.

### Psychological support for parents of a child with type 1 diabetes

Many recommendations, including those from ISPAD and ADA, recognize the role of the family as key to therapeutic success. The diagnosis of T1D forces the reorganization of the everyday life of the child and their caregivers, often forcing one of the parents (usually the mother) to quit work. The psychosocial consequences of T1D for families are extensive and the burden is increasing [21]. Initially, the period of intensive in-patient education in the hospital environment, followed by the adaptation to self-care and self-management at home, and the need to support a child in a difficult moment of life, constitute a huge challenge [9]. Approximately, 24% of mothers and 22% of fathers meet the criteria of post-traumatic stress disorder six weeks after the diagnosis of T1D in their child [22]. Knowledge about T1D and self-care provided to the young person and parents in the course of education (its manner, effectiveness and scope), financial possibilities, the age of the child and the level of support needed (much more responsibility on parents/caregivers with toddlers and younger children), but also personal beliefs, being overwhelmed with negative emotions including sadness, anger and grief, or difficulty in accepting the child’s new conditions are factors that may relate to non-compliance with medical recommendations in every-day life. Therefore, it seems necessary to provide psychological support also to the caregivers of PWDs [9, 11, 12].

Recommendations highlight also the importance of shared decision-making and responsibility in diabetes management for adolescents with diabetes. Although each time it should be adjusted to the cognitive abilities and maturity of the young PWD, studies show that supporting a teenager with T1D in making decisions related to diabetes and co-responsibility for the effects of treatment lead to improved glycemic control and meeting treatment recommendations [23]. Achieving trustful and effective cooperation with young PWD seems particularly difficult due to the strong need for acceptance in adolescence.

A teenager's difficulty in adapting to effective self-management may be caused by the fear of a negative opinion by peers, related to the diagnosis of a chronic disease itself, visible specialist equipment (sensor, insulin pump) or the need for hospitalization and the related absenteeism from school [9]. Psychological support in accepting diabetes and understanding the real personal impact on treatment results, well-being, and the possibility of avoiding early and late diabetes complications is of great importance in the therapeutic process [23].

### From the psychologist's point of view

The diagnosis of T1D evokes many difficult emotions in the PWD and their caregivers. It is a critical situation - the health and often life of the young person are at risk. During this period, it is natural for the child/teenager as well as for the parents/caregivers to experience shock, sadness, anger or disbelief. Usually, the diagnosis involves admission to the hospital, where, after the initial numerous medical procedures an intensive education on diabetes self-management is started in the following days, during which it is necessary to focus on learning new skills (injections, insulin pump therapy, carb-counting etc.) to effectively manage diabetes. The stress caused by the new situation can effectively hinder the acquisition of this new knowledge, which is also overwhelming. This is one of the fields in which the child and family can benefit from professional psychological support. Dissociating from an excess of difficult and flooding feelings (fear, sadness, guilt, anger and alike) is an important component of the therapeutic process at this point [24].

Supporting the whole family at the time of diagnosis may also have an impact on how parents experience and think about T1D. It is very likely that their beliefs will also apply to the child and affect his or her response to diabetes. The effect of the diagnosis and change of the family's situation on the siblings should also be considered. Therefore, undertaking appropriate psychological interventions from the very beginning is important and might prevent or reduce possible subsequent difficulties in the treatment process [25]. It has been shown that psychological and educational interventions in children and their families promote problem-solving skills and increase parental support in the early stages after diagnosis as well as improve long-term glycemic control in children. Moreover, treating the family as an integral part of the treatment process and applying family-based behavioral methods such as positive reinforcement, behavioral contracts, goal setting, self-control, parental support messages and appropriate sharing of diabetes management responsibilities, improve treatment compliance and glycemic control [26].

An important part of effective diabetes self-care is the location of health control. It seems better if young PWD and their families make behavioral changes tailored to the therapeutic requirements not in a passive, but in a creative and active way. One of the important factors in successful behavior change is becoming aware of one's beliefs regarding their own agency in taking care of ourselves in the new situation – living with T1D. If a PWD and their family believe that achieving glycemic targets

is only a matter of chance, without any impact of the PWD decisions, it indicates an external sense of control. In the therapeutic process it is important to equip the PWD and the caregivers with knowledge and beliefs about their own effectiveness and ability to influence health outcomes, such as glycemic values – and to support the establishment of the internal locus of control. People characterized by this type of control are more responsible for their health, as well as for the treatment or rehabilitation process. It was shown that PWDs with an external sense of control, who believe that others or fate are responsible for their health, have higher levels of glycosylated hemoglobin (HbA1c) [27].

Another important component of the child's and family's adaptation to sudden changes, one's resilience, self-esteem and perceived quality of life, and the methods of coping with stress [28]. These can be adaptive, including acceptance, cognitive reevaluation, problem-focused coping, seeking social support, or non-adaptive, which include: denial, avoidance, aggressive expression of anger, and turning to psychoactive substances.

A study involving adolescents showed that coping strategies and role-playing exercises contributed to better psychological functioning. The application of the effectiveness theory to improve learning skills in society and to resist peer pressure resulted in improved glycemic control after 4 months compared with those undergoing standard group diabetes education. In addition, in a randomized controlled trial, coping skills training, including social problem solving, conflict resolution, and cognitive behavior modification, improved metabolic control, self-efficacy, and coping. Although not all studies show improvement in glycemic control after an intervention, they demonstrate other benefits. For example, the results obtained by Mendez and Belendez revealed that adolescents in a group program that included education, discussion about stress and relaxation exercises, the concept of self-control and social skills training, reported fewer obedience barriers, less daily hassle, and better social interactions than those in routine diabetes care [29].

The psyche, as an inseparable part of every human being, should be taken into account in the treatment of any chronic disease, including T1D. A young person may find doctors and nurses judgmental and 'the part of the problem' and be more likely to talk openly with an independent person – a therapist or a psychologist. Thanks to the reassessment process that takes place during interviews, which leads to adjustments in beliefs and coping behaviors in the light of their own experiences, a PWD and his family can improve behaviors and modify the beliefs that are not serving health. In parallel with the objective rational process, at an emotional level, a similar process takes place in which PWDs develop coping behaviors to manage their emotional perceptions [26].

### Availability of psychological care for persons with diabetes

One of the first reports analyzing the availability of psychological care for children with T1D and their families was an online survey conducted in 2014. One hundred and 55 partici-

pants from 47 countries completed the survey addressed to doctors on the scope of implementation of the ISPAD recommendations on psychological care. It showed that a psychologist was included in the multidisciplinary diabetes teams in 56% of centers. Among them, in 43% of centers a psychologist participated in routine visits, and in one-fourth of the centers, a psychologist took care of all patients within the institution. Most (79%) of the teams made it possible to obtain specialist help to solve psychosocial problems and problems related to medical compliance, but almost 30% of the teams could not provide their patients with constant access to psychological support. It has been observed that access to psychological care is more often possible in larger centers and in those located in Europe and North America [30].

The differences in access to psychological care in pediatric diabetes clinics depends often on countries and local standards. In Ireland, in 2016, there were only 3 psychologists working part-time in three Dublin-based clinics, with no access to psychological care in the other 16 clinics across the country. This has been acknowledged and psychological support is now available in more clinics around the country, although the gaps in dedicated paediatric diabetes psychosocial care were identified across the whole country in 2022 [31].

Authors from Germany aimed to analyze the frequency and impact of psychological care on the parameters of metabolic control and the presence of acute T1D complications in children and adolescents. More than 30,000 children with T1D were included in the study. 39% of them ( $n = 12,326$ ) received a short-term or continuous psychological care. Although the authors noted that psychological assistance was provided to those with higher baseline HbA1c levels, they indicated that providing constant psychological care was associated with

stable glycemic control and less severe hypoglycemia during follow-up [32].

To the best of our knowledge, there are no other data on the availability of psychological care in centers treating children with T1D in Poland or other international data.

An important aspect, which is undoubtedly related to the availability of psychological care, is its financing. It seems that many health care systems do not fund a psychologist as a member of the diabetes team and their employment may in such situations constitute the cost of the team or diabetes unit/center, or the patient is charged with the payment for a psychological consultation. The above statement is based on the authors' personal observations, but unequivocal data on this topic are lacking.

## Summary

Despite the numerous publications and clinical recommendations suggesting the need for psychological care for PWDs and their caregivers, limited data is available on the actual availability of such care, both in Polish and international centers. Obtaining this information as well as data regarding the potential impact of available psychological care on the PWDs' glycemic control, could constitute an important basis for the updated recommendations. It would also help to emphasize how the clinical recommendations relate to reality. Carrying out analyzes on how including a psychologist in the therapeutic team and various aspects of psychological care offered in centers, rather than individual psychological interventions, are related to the results of glycemic control, would allow verification and optimization of psychological care and support for the youth living with diabetes and their families.

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